



# GETTING INVOLVED IN AGEING RESEARCH:

A GUIDE FOR THE COMMUNITY AND  
VOLUNTARY SECTOR

C|A|R|D|I

Centre for Ageing Research  
and Development in Ireland

---

**DR BRENDAN MURTAGH**  
QUEEN'S UNIVERSITY BELFAST

---

This publication was written by Dr Brendan Murtagh Queen's University Belfast on behalf of CARDI. It may be referenced as "Getting involved in ageing research: A guide for the community and voluntary sector" (2015), Centre for Ageing Research and Development in Ireland (CARDI): Dublin & Belfast.

---

June 2015

# CONTENTS

<b>Introduction</b>	4
<b>What is this guide for?</b>	5
<b>Two things to think about</b>	5
<b>The first thing to think about</b>	5
A. Concepts and creating the research idea	5
B. Ethical practice and vulnerability	6
C. Research governance	7
<b>The second thing to think about</b>	7
D. Data collection	7
E. Analysing the data produced by the research	8
F. Disseminating the findings	8
<b>Conclusion</b>	9
<b>Appendices</b>	10
I. Ten things you need to think about	10
II. Key terms in research	11
III. Types of user involvement	12
IV. Further reading and resources	13

W

# INTRODUCTION

In 2014 CARDI published a report, 'Building Stronger User Engagement in Age Research' (CARDI, 2014), which reviewed the nature of user involvement in academic research and how this can be strengthened to improve the quality of ageing research in Ireland, North and South.

This companion publication is a guide aimed at community and voluntary sector organisations that are being invited to assist or partner with others to conduct ageing research but is also relevant to those commissioning or undertaking evaluations of research.

Research is critical in advocacy campaigns, challenging policies and programmes, and thinking through new ideas and innovation for an ageing society. Various types of evidence help organisations, older people and researchers improve services, policies and practices, especially where they put older people at the heart of the research process. It is also important that research is conducted professionally and that organisations and older people are realistic about the scope of their participation in the preparation and the use of data gathered in particular projects. The key is to get the right balance between researchers, older people and community and voluntary sector organisations to ensure that research is useful, relevant and makes a difference, especially to the most vulnerable older people.

## WHAT IS THIS GUIDE FOR?

Research is a vital tool for the community and voluntary sector in understanding more about older people's concerns, evaluating the impact of policies and programmes, and supporting lobbying activities. The sector is increasingly being invited to assist or partner with a range of different stakeholders: universities, government researchers, think-tanks and the private sector to create better knowledge about ageing in Ireland, North and South. There are significant opportunities and benefits to such involvement including broadening the knowledge base about ageing and older people's experiences; giving older people a meaningful voice; creating a new programme of care and services; raising the profile of organisations; prioritising older people's concerns; challenging policy delivery; and making sure advocacy campaigns are based on the experiences of those most affected by service delivery.

However, in these interactions community and voluntary sector organisations often feel they are brought in too late or in superficial ways to projects. Some say they lack an understanding of research methods and processes and do not have a sufficient role in the design and delivery. Others feel that they and older participants are often properly rewarded or respected for their contribution to academic projects in particular.

This guide responds to issues raised by community and voluntary organisations in order to strengthen awareness of the value of research to the sector, older people, policy makers and the business community. In particular, it provides a framework to help you think through some of the issues when partnering, commissioning, or assisting others in research. It also explores how to get the best value from projects and what to do to avoid things going wrong.

The appendices to this document provide an easy to follow list of key issues to address when undertaking age research or getting involved in a project with a partner (App I), glossary of commonly used terms in research projects (App II), a listing of types of user involvement (App III) and further reading and links to resources on user involvement in research (App IV).

In summary, you need to be clear about the research aims, what you are being asked to get involved with, your role and responsibilities, and the implications including resources, time commitments and older people's well-being. It also suggests that research is conducted in ethical and meaningful ways that respects the interest of older people and community and voluntary organisations in the design and use of the data collected.

# TWO THINGS TO THINK ABOUT

It is important to think about 'research data' and the way in which it is designed, implemented and disseminated. Community and voluntary organisations and older people have critical roles at each stage, not to control or own the process but as active and valued stakeholders, to improve quality and ensure that it is useful and usable. Two key issues are important:

- First, you need to think about your role at the design stage and how you and older people are involved in deciding what is important to research, how issues are prioritised and in what ways older people will be involved in framing the key questions.
- Second, you might think about how the information that is produced is useful to you, the types of campaigns or issues that you think are important and crucially how they are used to advance the rights of older people in Ireland, North and South.

## THE FIRST THING TO THINK ABOUT

These questions highlight the need to take stock before, during and after the research process. Most organisations do this in very practical ways and here we suggest that you may want to adopt a simple checklist at key stages of the research process to ensure that it aligns with your organisation, value base and priorities (See App I). This section is mainly concerned with designing the project.

### A. Concepts and creating the research idea

At the outset it is important that you are given time to think through what the research is about, how it matches your priorities and whether it best reflects the interests of older people. Some questions to be considered:

- What is the research about, how does it align with our organisational needs and is it important for us or for older people?
- Who benefits most from the research and are there potential risks by being involved?
- How will we be engaged at key stages of the process especially in the research design, consideration of the methods being used, conduct of fieldwork and use of the data?
- How would we use the research: to advocate and lobby for change; to know more about an issue or problem; to improve public services; to design a new approach within our organisation; or develop new clinical treatments?
- Are we being employed as gatekeepers to access research settings, other agencies or public bodies and especially older people themselves? How are our responsibilities to those who we help access protected?

### **The priority activities at this stage might include:**

- Discuss the project and how it reflects the needs of the organisation and older people, and how the research might be amended, developed or refined to more effectively impact on you and/or your work.
- Review and evaluate the research idea or proposal from the perspective of older people and possibly use them to undertake such analysis.
- Identify where older people could be involved in the project for example design, implementation and/or dissemination.
- Work with researchers to ensure that there is sufficient time to consider and develop the research concept or application process.
- Ensure, where it is practicable, that your organisation is named as a key part of the research project for example built into costings where it is in your interest and is appropriate, you must in turn allocate sufficient time to deliver.
- Create realistic expectations about the research, the time taken to take part, the timeframe for implementation and when and in what format the outcomes from the research will be made available to users.
- Be realistic, especially with older participants, about the role of research in policy change or discovering new treatments for specific conditions and illnesses.

## **B. Ethical practice and vulnerability**

The value base and ethics of the research are key mechanisms to ensure that the project meets the needs of your organisation and older people. Some questions to consider include:

- Has the project been formally ethically reviewed and have you seen the documents relevant to ethics applications and assessment?
- Who conducted the review, when and what mechanisms were used such as a university ethics committees or approval through government health and social care procedures?
- What risks have been identified and do you think a full account has been taken of the impact on vulnerable older people in particular? Are you satisfied that the risks identified have been properly mitigated both for community and voluntary sectors, partners and older people?
- What methods have been used to recruit older people as participants and are they adequate?
- Is information about the project, participation and use of data clearly presented in a way that subjects and users can understand? Have the researchers prepared an information sheet aimed at the lay reader?
- What are the procedures for gaining informed consent from older people as research participants; is it written or verbal and have you seen the forms being used?
- How is the data going to be stored and is the information securely and confidentially held especially where it relates to sensitive medical records or results?

## C. Research governance

As well as having a clear understanding of the type of research and its application, it is also important that participating organisations have a say in its design, delivery and application. Issues to consider include:

- What structures have been established to include different stakeholders in the management of the research?
- How large are such groups; are there other governance mechanisms for the project and how do they relate to each other?
- What are the terms of reference of research project boards or management groups in particular projects?
- Are you centrally involved in decision making or are you purely representative?
- Are older people involved for example through a user panel or reference group?
- How are participants rewarded in terms of time commitment, access to data or in real cost terms? Are older people being paid or reimbursed for their participation (note the distinction and the legal framework that apply to payments)?
- Have the costs of your organisation's participation been properly accounted for in research bids?
- Do participants have a clear understanding (including a written description) of their roles, the time it will take and practical implications of getting to and from user events?

## THE SECOND THING TO THINK ABOUT

This stage involves the implementation and application of the research, and is vital to better reflect the needs of the community and voluntary sector and older people rather than just the interests of professional researchers. It is important that you can contribute to the development of these stages in order to strengthen the relevance and impact of a project.

## D. Data collection

A number of innovative projects have used peer researchers to gather quantitative and qualitative data. This shows that with appropriate training older people can play an active role in producing as well as using research.

- Researchers and community and voluntary organisations need to agree if it is appropriate for older people to collect data and whether such involvement will add to the quality of the project.
- If deemed appropriate older people will also need to understand how to collect data and researchers need to properly plan engagement methods.
- Older people may need training in research methods as well as in the specific data collection techniques they will be using.
- Determine the training and on-going support that they will need in analysing and evaluating the data.

---

<sup>1</sup> If you are making payments (as distinct from reimbursement) to members of the public engaged in your research, then you need to be aware of the legal frameworks that apply and it is worth reading guidance published on the INVOLVE website on payment for involvement in research. To summarise, payments (not reimbursements) are subject to Employment Law; counted as taxable income (and thus also subject to National Insurance) and may affect entitlement to state benefits and allowances.

There is a range of methods to achieve user engagement and these have been set out in Appendix III of this document. These can be as informal as Steering and Advisory Groups or more structured User Groups and Deliberative Panels, and each one has different strengths and weaknesses in ageing research. There is no single best approach and it is important that community and voluntary organisations define what is most appropriate, suitable for the older people they serve or represent and be realistic about what can be achieved in individual projects.

## E. Analysing the data produced by the research

The community and voluntary sector and older people can bring a fresh perspective to the interpretation of data, prioritising issues and seeing connections from the positions of different users.

- Researchers should clarify, explain and help older people to interpret data from their own perspective.
- Opportunities to involve older people in the identification of priorities, gaps and issues for further analysis should be encouraged where this is practicable.
- Researchers should also try to present data, especially more complex statistical analysis, in a way that older people can understand, engage with and offer insights.
- Initial data could also be circulated to the set of stakeholders identified for the project. This could invite responses individually or as a group to help broaden the analysis of the information.
- Researchers, older people and community and voluntary organisations should ensure that time and resources are put in place to allow engagement, dissemination and discussion.
- A range of data outputs and translation methods should be used to maximise the sharing of the research findings.

## F. Disseminating the findings

The final part of the research process is one of the most important for older people and the community and voluntary sector. It is essential that the research makes sense to both and acts as a basis to challenge services, improve treatments, advocate for better policies and develop new approaches.

- Researchers should work with community and voluntary organisations and users to present a summary or briefing report aimed at the lay reader.
- Think where and how to disseminate the findings based on mapping your stakeholders at the start of the process.
- Consider using older people and the organisation staff's expertise to help inform the final reports and summaries. Older people should play an active role in explaining the research, presenting its findings and identifying the implications for policy and practice.
- Also consider disseminating research in a range of formats. This will depend on time and resources but might involve posters, summary leaflets, newsletters, video format or online materials.



# CONCLUSION

This guide is designed to provide a framework to enable community and voluntary sector organisations to think through the implications of research for their work and for older people. Research is a vital tool in improving older people's lives and is critical for organisations concerned with ageing and olderpeople.

This guide is designed to support community and voluntary sector organisations to think through the implications of research for their work and for older people. It provides a framework to help understand how to maximise the benefits of getting involved in research projects and partnerships.

# APPENDICES

## I. TEN THINGS YOU NEED TO THINK ABOUT

To sum up, we suggest that you might want to ask a series of questions relevant to the design, delivery and dissemination of research:

1. Is it clear who the research is for and why you are asked to be involved; and do you feel that the stakeholders are properly mapped out in community and voluntary organisations and older people are clearly defined as beneficiaries?
2. How useful is the research to you and older people you work with? Can you easily identify the likely value or impact of the project and can these be strengthened for example, through stronger involvement of older people, users and community and voluntary organisations, and through a stronger link to policies and services?
3. Have you influence on how your organisation and older people could be appropriately and effectively involved in the research project?
4. Have the ethical implications of the research been clearly explained to you; are there risks or potential harm to older people; can the design and delivery of the project be improved to address any ethical concerns?
5. What impact will the research have on you as a participant? Does it have implications for your services, capacity to participate, reputation or resources (is there a cost to you or the older people to participate)? For new projects will you be named as a co-applicant in grant applications and will there be a specific budget covering your involvement?
6. Are there appropriate organisational structures and management arrangements in place to enable you and where relevant older people to participate properly in the key stages of the research?
7. Is it appropriate and if so is there potential for older people to play a role in data collection; what is the level of commitment required for example what support and training will they receive?
8. Are you given an opportunity to comment on the methodology to ensure user involvement in the design, management and implementation of the project?
9. Is there a dissemination strategy in place which is useful to community and voluntary organisations and will it produce findings in ways that are accessible to older people and advocates?
10. Do you, your organisation and where relevant older people have the skills and resources to participate in the research effectively?

## II. KEY TERMS IN RESEARCH

Term	Definition
Case Study	The collection and presentation of detailed information about a particular participant or small group frequently including the accounts of subjects themselves.
Control Group	A group in a research project that receives an intervention in order to compare the group against one which did not.
Data	Recorded observations usually in numeric or textual form.
Ethnography	The goal of this type of research is to comprehend the particular group/culture through observer immersion into the culture or group. Research is completed through various methods which are similar to those of case studies but since the researcher is immersed within the group for an extended period of time more detailed information is usually collected during the research.
Qualitative Research	Research in which the researcher focuses on text and voice rather than quantitative/numerical data. Case study, observation, interviews and ethnography are considered forms of qualitative research. Results are not usually considered suitable to be generalised but are often transferable.
Quantitative Research	Research in which the researcher explores numeric significance of the data. Survey is generally considered a form of quantitative research. Results can often be generalised though this is not always the case.
Random sampling	Process used in research to draw a sample of a population strictly by chance, yielding no discernible pattern beyond chance. Random sample selection is used under the assumption that sufficiently large samples assigned randomly will exhibit a distribution comparable to that of the population from which the sample is drawn.
Sampling Frame	A listing that should include all those in the population to be sampled and exclude all those who are not in the population.
Sample	The population researched in a particular study. Usually attempts are made to select a 'sample population' that is considered representative of groups of people to whom results will be generalised or transferred. Sample size is critical and generally the larger the number in the sample, the higher the likelihood of a representative distribution of the population.
Survey	A research tool that includes questions which are either open-ended or close-ended and employs an oral or written method for asking these questions.
Triangulation	The use of a combination of research methods in a study. An example of triangulation would be a study that incorporated surveys, interviews and observations.

Source: <http://writing.colostate.edu/guides/guide.cfm?guideid=90>

### III. TYPES OF USER INVOLVEMENT

The table below is taken from CARDI's user engagement guidance 'A Guide to User Involvement in Ageing Research (2014)' and might help to give you a choice about how to best influence the project with which you are involved.

<p><b>Steering and Advisory Groups</b> that help to manage research projects provide an important opportunity to engage older people. It is best to consider more than one participant and to ensure that they are properly briefed on the nature of the work to be able to engage effectively.</p>
<p><b>Public meetings</b> provide an opportunity to consult large numbers of older people. Meetings can be organised to allow for small group discussions with oral feedback. They offer opportunities for participants to set or influence the agenda and to ask questions about the research and its design. More general meetings are good for scoping the research design, surfacing issues from users and feeding back results to larger groups.</p>
<p><b>User Forums</b> are a regular meeting of older people and typically comprise members of civic, political, professional, economic or social groups with an interest in a specific age issue (rural isolation, dementia carers and so on). Forums can be a useful way of involving groups that are traditionally excluded from decision-making processes, such as older people. However, it is often the 'usual suspects' or those who are already involved in organisations who will participate.</p>
<p><b>Discussion groups</b> enable formal and informal groups to listen to the views of older people. They often provide a way to avoid using older people purely as a resource and it might be possible to keep a standing group informed with newsletters, informal contacts and feedback sessions.</p>
<p><b>Direct participation</b> involves directly recruiting older people and training them to undertake survey interviews, group discussions, in-depth interviews and where relevant literature and policy reviews. In these ways older people bring their experiences to bear in the collection and analysis of various forms of data.</p>
<p><b>Web based engagement</b> may not always suit older people but their use of the internet and social media in particular is growing. There are a variety of web-based engagement processes to choose from such as online discussion forums and blogs, Facebook, online surveys, social networking, ratings and voting and digital interactive TV. Web-based activities enable people to choose where, when and for how long they want to participate.</p>
<p><b>Citizens' Juries</b> involve a group of older people who are representative of the wider group to consider a complex issue by gathering evidence, deliberating and then reaching a decision. Jurors can 'cross examine' expert 'witnesses' (the researchers) who may offer differing perspectives on the issue or topic at hand before reaching agreement or producing a short report of recommended actions. Normally an advisory panel with expertise in the area considers the jury's findings or report and determines what, if any, actions should be taken. A variation of the method is Citizens' Panels which involve ongoing panels of around 1,000 to 2,000 people who are representative of the age community and the panel is surveyed several times a year by post, telephone or online.</p>
<p><b>Deliberative Panels</b> are useful for forming research ideas especially where the subject is complex and uncertain. People are invited to join a panel related to a specific project to represent the views of everyday people. A panel should be made up of a broad range of people to better represent the older community and its views. A deliberative panel is educated by the researchers by being given information, receiving presentations and attending discussion groups and their views are obtained on an ongoing and iterative basis.</p>

Source: CARDI (2014) A Guide to User Involvement in Ageing Research  
<http://www.cardi.ie/sites/default/files/publications/cardi-execsummary-UserEngage-FINAL.pdf>.

## IV. FURTHER READING AND RESOURCES

It is important that research has as much impact as possible and this resource helps to think about building impact into the design as well as the use of research across social sciences, engineering and medicine:

<http://www.rcuk.ac.uk/ke/impacts/>.

INVOLVE provides detailed guidance, case studies and resources to strengthen participation in research. INVOLVE (2012) Briefing Notes for Researchers: Public Involvement in NHS, Public Health and Social Care Research, London, INVOLVE:

<http://www.invo.org.uk/>.

The European Research Area in Ageing 2 (ERA-AGE 2) provides a range of resources to support user engagement including a specific report (Barnes, M. and Taylor, S. (2009) Summary Guide of Good Practice for Involving Older People in Research, London, ERA-AGE) on the involvement of older people:

<http://era-age.group.shef.ac.uk/assets/files/05.01.2009kc%20%20User%20Involvement%20Good%20Practice%20Guide.pdf>.





# C|A|R|D|I

Centre for Ageing Research  
and Development in Ireland

---

Centre for Ageing Research  
and Development in Ireland

Forestview  
Purdy's Lane  
Belfast BT8 7AR  
Tel: +44 (0) 28 9069 0066

5th Floor Bishop's Square  
Redmond's Hill  
Dublin 2  
Tel: +353 (0) 1 478 6308

Email: [info@cardi.ie](mailto:info@cardi.ie)  
Web: [www.cardi.ie](http://www.cardi.ie)